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Parents' reactions to testing for herpes simplex virus type 2 as a biomarker of sexual activity in Botswana junior secondary school students

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Abstract

Background—Use of sexual activity biomarkers in HIV prevention trials has been widely supported to validate self-reported data. When such trials involve minors, researchers may face challenges in obtaining parental buy-in, especially if return of results procedures uphold the confidentiality and privacy rights of minors and preclude parental access to test results. In preparation for a randomized controlled trial (RCT) with junior secondary school (JSS) students in Botswana, a formative assessment was conducted to assess parents' opinions and concerns about testing for herpes simplex virus type 2 (HSV-2) (biomarker of sexual activity) as part of the RCT.

Methods—Six focus groups were held with parents (n = 32) of JSS students from urban, peri-urban and rural communities. Parents were asked their opinions of students being tested for HSV-2 and procedures for blood sample collection and return of results.

Results—Overall, parents were supportive of HSV-2 testing, which they thought was a beneficial sexual health resource for adolescents and parents, and a motivation for parent–child communication about HSV-2, sexual activity and sexual abuse. Some parents supported the proposed plan to disclose HSV-2 test results to adolescents only, citing the importance of adolescent privacy and the possibility of HSV-2 positive adolescents being stigmatized by family members. Conversely, opposing parents requested parental access to results. These parents were concerned that adolescents may experience distress following a positive result and withhold this information thereby reducing parents' abilities to provide support. Parents were also concerned about support for victims of sexual abuse.

Conclusion—Although the present study demonstrates that parents can be accepting of sexual activity biomarker testing of adolescents, more research is needed to identify best approaches for returning test results.

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CONFLICTS OF INTEREST

None declared.

The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the CDC.

Additional keywords

biological outcomes; HIV research; parental acceptance; parental perception; sexual activity biomarkers

INTRODUCTION

Preventing HIV infection among adolescents is an urgent public health priority, especially in sub-Saharan Africa, where 80% of all HIV-positive young people (15–24 years) lived in 2010.[1] Given that the primary mode of HIV transmission in this region is through heterosexual intercourse,[2] interventions that aim to delay sexual initiation, reduce number of sexual partners and promote safer sex behaviors are common prevention strategies.[3] However, the rigor of research that informs these interventions is undermined by reliance on self-reported data to demonstrate program effectiveness.

Self-reported sexual activity data is fraught with validity issues due to social desirability bias, recall bias and measurement error.[4–7] The validity issues in self-reported sexual activity data from adolescents in sub-Saharan Africa[8–12] and other parts of the world[13,14] are well documented in the literature, and could be attributable to the social consequences associated with early sexual activity and the secretive nature of adolescent sexual relationships in many societies.[10,14] To that end, the field has advocated for the use of objective biological markers (biomarkers) – such as HIV and sexually transmitted infection (STI) status, pregnancy, and markers of semen exposure – to validate self-reported sexual activity.[5,15] As a result, recent studies evaluating HIV sexual risk reduction interventions for adolescents in sub-Saharan Africa have taken the approach of comparing participants' self-reports of sexual behavior to their HIV and STI status.[16–18]

However, this approach may raise concerns about parental access to confidential clinical test results. Parents and guardians (hereafter referred to as parents) are the key decision-makers in consenting for adolescent minors to participate in research. Despite the recognition of parents' key role in research involving minors, parental perception of sexual activity biomarker testing of adolescents remains understudied. We conducted a literature search and identified only one study that reported on parents' opinions of study procedures that included sexual activity biomarker testing.[9]

Examining parental views on sample collection procedures, which include blood draws, vaginal swabs, or urine analysis, are also important because parents may find these procedures invasive or unacceptable and prohibit their child from participating. Of equal concern is the procedures for the return of test results. As medical decision-makers for their child, parents may request that test results be released to them, or they might prevent their child from participating. However, providing test results to parents may be a violation of adolescents' confidentiality and may discourage them from participating in the study.

Despite these challenges, studies utilizing sexual activity biomarkers on adolescent populations are still feasible. In order to conduct such studies in a manner that is acceptable to parents, researchers need to understand parents' perceptions and concerns about sexual

activity biomarker testing. A formative assessment was conducted to assess parents' opinions and concerns regarding testing junior secondary school (JSS) students for herpes simplex virus type 2 (HSV-2) as a biomarker of sexual activity, in preparation for a randomized controlled trial (RCT) that will evaluate the efficacy of a HIV behavioral risk reduction intervention in Botswana.

METHODS

Focus group discussions (FGD) were conducted to explore parents' opinions and concerns of JSS students being tested for HSV-2, blood sample collection procedures and plan to return results only to adolescent participants in the proposed RCT.

Recruitment

Purposive sampling techniques were used to recruit parents from three schools in rural, urban and peri-urban communities (one school per community) in the north-east and south-east districts. Schools were selected based on demographic similarity to the RCT schools and interest in participating in the formative assessment. To avoid contamination, the chosen schools will not be included in the RCT. A point of contact was appointed at each school to identify and recruit eligible parents to participate in the study. Eligibility criteria for the FGDs included being a parent or guardian of an adolescent (13–17 years old) enrolled in a JSS study site, residing or working in the same district as the selected school and speaking English and/or Setswana. To maximize participation, FGDs were conducted within 3 or 4 days of recruitment.

Data collection

FGDs were conducted in English or Setswana, and moderated by local staff trained in focus group moderation. At the beginning of each FGD, moderators read the consent form to parents and collected signed consent forms from them. The moderators provided parents with a factsheet on HSV-2 and procedures for testing and return of results, which had been prepared for the proposed RCT. Testing procedures for the proposed RCT included using a finger-prick for blood sample collection and returning test results to adolescent participants only. RCT participants would be provided with counseling at the time of testing and return of results, and information about local resources for additional counseling and care services. Parents were also informed that parental permission would be required for minors (less than 18 years old) to participate in the RCT. The moderators then led the parents through a discussion about their opinions and concerns about the HSV-2 testing component of the trial.

No personal identifiers other than the informed consent form were collected from parents. FGDs were mixed-gender, held on school grounds and each lasted ~1.5 h. Light refreshments were provided and transportation assistance was available upon request. Ethical approval was obtained from the USA Centers for Disease Control and Prevention and Botswana Ministry of Health (MOH) and Ministry of Education and Skills Development (MoESD).

Data analysis

Focus group discussions were digitally recorded and transcribed into English. Transcripts were reviewed and compared against the audio recording for accuracy, de-identified and imported into MAXQDA (a qualitative management tool developed by VERBI GmbH located in Berlin, Germany) for analysis. Themes related to parents' opinions and concerns about the HSV-2 testing component of the proposed RCT were identified by three research team members based on recurrence and similarities and differences noted across the transcripts.[19] A code book consisting of key terms and their operational definitions was subsequently developed. Using the code book, two team members independently coded the transcripts, meeting frequently to reconcile any discrepancies. Text labeled with each code was analyzed descriptively and relationships between themes were examined.

RESULTS

Demographics

Six FGDs were conducted in March 2012, with parents (n = 32) of JSS students from the three chosen study schools. Of the 32 participants, 27 were female, 2 were male, and gender was unknown for 3 of the parents.

Summary of Main Findings

All parents were supportive of HSV-2 testing, which they perceived as a beneficial sexual health resource for adolescents, and a motivator for parent–child communication about sexual health. Additionally, the HSV-2 information handout provided an unexpected sexual health learning opportunity for parents. Parents did not raise any objections to the blood sample collection procedures, but had mixed reactions to the procedures for return of results. Some parents supported the proposed plan to disclose HSV-2 test results to adolescents only, citing the importance of adolescent privacy and the possibility of HSV-2 positive adolescents being stigmatized by family members. Conversely, opposing parents requested parental access to results. These parents were concerned that adolescents may experience distress following a positive result and withhold this information, thereby reducing parents' abilities to provide support. They were also concerned about the impact of this distress on adolescents' wellbeing

Sexual health resource

Overall, parents had a positive reaction to the inclusion of HSV-2 testing. In fact, many said they would give permission for their child to participate in the proposed RCT, should they be selected. They noted that risky sexual behavior is a serious problem among adolescents, which needed to be addressed. As such, they were supportive of HSV-2 testing, which they felt was a needed sexual health service that will educate adolescents in Botswana about STIs and give them access to screening and treatment should they acquire an STI. As illustrated by one parent: '*I think it is okay. It encourages good behavior in kids. And it's ok if they get tested as early as possible to get help.'* [FGD 2, Mother] A similar sentiment was echoed by another parent: '*I personally understand why it is in this study. Because now our children*

live a very different life from us more so their lives are in danger. This study will help them.' [FGD 1, Mother]

Unexpected sexual health benefit to parents

Surprisingly, a few parents also felt that the inclusion of HSV-2 testing in the study will directly improve their own sexual health knowledge and encourage them to seek treatment services. Most of the parents were not aware of the association between HSV-2 and genital sores and learned about it for the first time from the HSV-2 handout and FGDs. A respondent shared that the HSV-2 information given to parents will help them recognise herpes sores – should they get them – and encourage them to visit the clinic for further evaluation:

> 'I wanted to add on, as parents and as we are sitting here, we also wouldn't even understand some things, especially about this kind of virus. And I believe that as parents we will also take care of ourselves and be aware of the sores that can come. And then you will be able to run to the hospital and get help.'
>
> [FGD 1, Mother]

Sexual abuse discovery

Though neither the trial information sheet nor the discussion group questions introduced the topic, respondents in one discussion group twice brought up implications of testing for adolescents who have experienced sexual abuse. A parent advised that there could be adolescents who learn through positive HSV-2 test results, that they were sexually abused while intoxicated:

> 'There are also those who think that they have never engaged in sexual relations, but they have been drunk. They have been intoxicated by friends, their relatives, and they have been used…. And when there is this virus, this will reveal that something has happened to the child.'
>
> [FGD 3, Mother]

Some parents believed that a positive HSV-2 diagnosis may motivate an adolescent to disclose a history of sexual abuse to a parent:

> 'Because sometimes, these children may not be [voluntarily] indulging in sexual relationships. There might be some abuse taking place there, and they have been keeping it a secret until they see this [positive HSV-2 test results] and say "ah Daddy, I have been keeping quiet about this but me and my uncle or me and my aunt have been doing this".'
>
> [FGD 3, Father]

They argued this would lead to more parent–child communication about child sexual abuse, which is difficult to discuss and a taboo topic in many societies.

Promote parent–child communication

Some respondents saw the proposed RCT and the introduction of HSV-2 testing as an opportunity for parents to begin building a close relationship with their adolescent, and have

open discussions about sexual health topics. One parent shared how the information sheets and FGD has given her the confidence to begin talking to her children about HSV-2:

> ‘I am also grateful but as you are teaching us, you are also counselling us. As parents we are going to teach our children because you have taught us. And I will say to my child I have learned this. And I know they will be skeptical to do it (HSV-2 testing), but when I am home I will inform my children that “this is very important for you.” If my child hears me talk comfortably about the sores she will be comfortable to talk to me about them and she will feel free to come to me and tell me “by the way mom, I have got these sores.” ’
>
> [FGD 1, Mother]

Another parent viewed HSV-2 testing as an opportunity to build a close parent–child relationship to help adolescents cope with the anxiety of taking the HSV-2 test and disclosing their results:

> ‘I think we should take advantage of the study to build that relationship to avoid that anxiety of my child taking the HSV-2 test and telling me the results.’
>
> [FGD 2, Mother]

However, not all parents thought that they could build a close relationship with their child to openly communicate about the RCT and sexual health issues:

> ‘Children will feel that the reason why parents are giving permission is because “maybe she [parent] doesn’t trust me anymore, does she suspect that I am already sexually active?” Is there going to be any counselling to reassure them that your parents did not ask for this? It is because they wanted to contribute to the community and country at large.’
>
> [FGD 1, Mother]

Sample collection procedures

Parents were asked to share their thoughts on collecting blood samples from adolescents via finger-prick using a lancet. They did not have an issue with the proposed approach given that adolescents are used to having their blood drawn for blood donation drives conducted at school:

> ‘We have gone through this kind of test. Whenever there is blood donations they are always being tested through the pricking of the finger [for HIV], so they have nervousness, and those who feel the pain, but they go “ahhh!” and then it is gone.’
>
> [FGD 3, Mother]

Return of results

Parents were asked their opinion about returning results in the proposed RCT to adolescent participants only upon request and via telephone. Additionally, adolescents who report any STI symptoms or have positive results will be referred to a local clinic. All adolescents will receive information about local sexual health resources and counseled before taking the test and when results are given.

Adolescents should be encouraged to get their results

All parents approved of the plan to return results via telephone. In regards to retuning results only upon request, many parents requested that study staff encourage adolescents to obtain their results, so that they would be aware of their status and change their behavior accordingly:

> ‘They should not just test and not know their results. Because they are still children and they might fear that “if I test and I get my results, what am I going to tell my mother?” ’ Please try to explain to them that we are not very much involved, it is up to you. Please encourage them to get their results’
>
> (FGD 1, Mother)

> ‘It is right for them to receive them, so that from then, they can be able to change their behavior, if they have the virus’
>
> [FGD 5, Mother]

Adolescents’ choice to tell their parents

However, their reaction to results only being released to adolescent participants but not parents was mixed. Some parents felt that adolescents had privacy rights and should decide whether to tell their parents. One parent explained this view:

> ‘Yes, it should come from our children. I should not force my child. Sometimes they don’t want their parents to know what is happening in their lives. And we want it to be confidential. There will be time to reveal the truth, but if he wants to come with the mother, he is free to do so.’
>
> [FGD 1, Mother]

Another parent felt that adolescents should decide whether to tell their parents, because in some families, an HSV-2 positive adolescent would be stigmatized by family members, thus compromising familial relationships. The parent added that in such cases, a positive HSV-2 test result could influence the adolescent to change his/her behavior without intervention from the parents:

> ‘Because some may go and share with their parents and their parent will be labeling them, some may not share and then live well in the family. And some secrets when they are shared they may destroy a family. So it’s better when the child says “ooh! I have done this let me change before my father knows about it.” Then they stop having sexual relationships because they have seen the bad results of it.’
>
> [FGD 3, Mother]

Study staff should share results with parents

While some parents felt that it is the adolescents’ choice to disclose the results to them, others felt that staff should also inform parents of test results. Those who felt that parents should be given test results thought that adolescents were secretive and would hide their test results:

> ‘I take it that if he or she is tested, definitely the parent will want to know the results of his or her child. Am I free to know them? Because sometimes these are small children and maybe they have this disease, but they are small and they can hide these kinds of things.’
>
> [FGD 4, Mother]

Some were concerned that adolescents may be distressed by a positive HSV-2 result and withhold this information, thus limiting parents’ ability to provide support and counselling. They were also concerned about the impact of that distress on various facets of adolescents’ lives, such as their education:

> After the results have come out, and the child knows his results, do you think it will affect him in his school work? Because this child will have kept it to himself, and as a parent I wouldn’t have had the opportunity to counsel my child, to talk to him as a parent. Don’t you think it will affect his life somehow, because keeping that secret can be a burden?’
>
> [FGD 4, Mother]

Other parents questioned adolescents’ level of responsibility to cope with the implications of their test results. They felt that parents, as the primary caregiver for their adolescents, should be allowed to obtain test results from study staff and felt that as the primary caregivers for their adolescent, they should know the test results:

> ‘When it comes to results, you as a parent who stood by that child all this time, the one who would understand the child’s health all of his life, you are not even involved? But this child is not responsible enough. If he was responsible, I would say its fine.’
>
> [FGD 4, Father]

While some parents concerns were alleviated when the comprehensive counseling and support plan, which will include referral linkage to a local health clinic, was explained, others still felt that parents should be allowed to receive their adolescent’s test results. The latter cited concerns about the adequacy of the counseling to alleviate the burden adolescents may experience from receiving a positive result and hiding it from their parents:

> ‘Is the counseling provided going to be enough for the kids to think “ok fine, I am not going to tell my parents”? Because at times it’s going to be hard, or the lifestyle of the child is going to change when they get home, if they feel that they are carrying a burden that they cannot share with their parent.’
>
> [FGD 3, Mother]

DISCUSSION

Understanding and addressing parental concerns about sexual activity biomarker testing and procedures for return of results remain critical areas to examine in adolescent HIV/STI intervention research. In our study, parents were very supportive of JSS students being screened for HSV-2 as a biomarker of sexual activity and did not have any objections to using finger-prick to collect blood samples and retuning results via telephone. However,

while some parents agreed with the proposed plan of returning results to adolescent participants only, others disagreed, stating that study staff should also release results to parents.

Parents' positive reaction towards HSV-2 testing of adolescents is similar to the findings of the study by Cowan *et al.* (2002)[9], the only study identified in our literature search that reported findings on parents acceptance of evaluation trials using sexual activity biomarkers. Specifically, it explored parents' perspectives on screening JSS students for HIV, gonorrhoea and chlamydia via urine samples, as part of an evaluation of a reproductive health intervention. However, unlike our study, the authors did not elaborate on parents' reasons for their acceptance of the sexual activity biomarker testing.

Our findings indicate that parents' positive reception of HSV-2 testing was primarily associated with the belief that it would provide adolescents with sexual health education and motivate them to avoid risky sexual behaviors. It is important to note that parents identified this benefit on their own without being prompted; neither the handouts nor the moderators, emphasized the sexual health education benefits of the HSV-2 testing component of the trial. Instead, these materials described benefits such as enhanced STI screening and design of more efficacious interventions for adolescents in Botswana.

While trials involving sexual activity biomarkers are designed to benefit adolescents, our findings revealed that such trials could also be beneficial to parents. Through the HSV-2 handout, parents acquired new knowledge about symptoms and treatment, which were motivate to seek treatment for the HSV-2 sores should they get them. A possible explanation for this unexpected finding is that most of the parents were not aware of the relationship between HSV-2 and genital sores before the FGDs. As a result, this finding may not be applicable to trials using sexual activity biomarkers that parents are familiar with such as HIV, which is widely discussed in Botswana.

Despite their overall support of HSV-2 testing, parents had several concerns. One concern was that positive test results would lead adolescents to disclose a history of sexual abuse, and as such, they questioned whether counselors will have the skills and abilities to respond to these disclosures. In the RCT, counselors will be trained on how to support victims of sexual abuse and will be knowledgeable of local sexual abuse resources that can provide further support to victims. They will also be required to report all disclosures of sexual abuse to a social worker in the district the child resides, in accordance with the Botswana Children's Act. Future research should consider whether parents should be provided with guidance on how to respond supportively to disclosures of sexual abuse from their adolescents.

Another concern was that adolescents would hide their test results, thereby limiting parents' ability to help their adolescents' cope with the stress of a positive result. Parents' beliefs that adolescents would be secretive about their results indicate poor or delayed initiation of parent–child communication about sexual health issues. The lack of parent–child communication is concerning, given that parents can play a vital role in helping adolescents accept and cope with positive HSV-2 results. Recognizing the important role they play as

support systems and sexual health educators for their adolescents, some parents were motivated to begin having these challenging but necessary discussions with their adolescents. As a result, it is critical to prepare parents to have these sexual health discussions with their adolescents. This can be achieved through the provision of educational materials or information sessions to improve parents' skills and knowledge to effectively communicate with their adolescents and support them if they test positive for HSV-2.

Upon learning about parents' concerns regarding the return of test results to adolescent participants only, the MOH and MoESD required that test results be provided to the parents of minors in the RCT, should they wish to know them. They believed that this change will help promote acceptance of the trial in the chosen RCT communities and give parents the opportunity to help their adolescents cope with the stress of a positive result. As a result, the RCT protocol was modified to reflect this change; the implications of which are yet to be determined for the RCT. Studies using sexual biomarker outcomes in sub-Saharan African settings have utilized both approaches of returning test results to adolescent participants only[9,16,20] and to participants (if under 18 years old) in the presence of a parent/guardian.[21] Returning test results to parents may result in adolescents refusing to participate out of fear of parents knowing their results, parents coercing adolescents to participate or stigmatization of HSV-2 positive adolescents by family members, as indicated by one parent in the FGDs. Conversely, parents may withhold permission for their adolescents to participate if they cannot access the test results. These issues highlight the need for more research to identify best approaches for returning test results, ones that meet parents' desire for involvement and protects adolescents' confidentiality. Future research should also examine adolescents' perspectives on HIV prevention studies involving biomarkers, especially procedures for return of results, which seem to be the point of contention in this type of research.

There are several limitations to this study. Findings may not be generalizable to settings that are not demographically and culturally similar to Botswana. In addition, the group setting and the nature of qualitative methods may have caused parents to overemphasize their approval for HSV-2 testing as part of the proposed RCT. These findings may not be applicable to studies that use sexual activity biomarkers that are heavily stigmatized, such as HIV, or require more invasive sample collection procedures, such as self-obtained vaginal swabs to test for a prostate-specific antigen – a biomarker for recent semen exposure.[12] Given that most of the participants were female, the opinions of male parents were underrepresented in the focus groups. A more even distribution of male and female participants may have helped to ensure a more comprehensive understanding of parents' perspectives on biomarker testing.

Despite these limitations, this study helps to fill the evidence gap in the literature exploring parents' opinions and concerns about sexual activity biomarker testing and can serve as a guide for other researchers employing a similar study design. If such trials are to be conducted, parental acceptance will be crucial to ensuring high participation rates and comprehensive emotional support for adolescents. The findings from this study demonstrate that parents can be receptive to trials that use biomarkers to measure adolescent sexual activity.

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